



Policy No. 109

Statement on Medically Fragile Individuals

Adopted April 27, 1990

The Developmental Disabilities Council supports the concept of families caring for their medically fragile family members in the family home. Whenever the option exists, the home (whether biological, adoptive, or foster) is the preferred environment for optimal emotional, psychological, and physical growth and development.

Individuals with intensive medical needs are living longer through advances in technology and they continue to need medical and other supports.

Families choosing to care for their family member at home should receive the necessary financial, medical, and service supports they need to assist them in that decision.

Public and private policy for medically fragile individuals should guarantee access to quality care for medically fragile individuals based on families' needs that is provided in the most appropriate, safe, nurturing setting possible.

It is the policy of the Developmental Disabilities Council that:

1. Placement decisions must be based on the safety and well-being of the individual who is medically fragile.
2. Families must receive the public and private support they need to care for their medically fragile family members at home.
3. When out-of-home care is necessary, the Council supports placement in an appropriately trained foster care home or small, specialized medical group home with continued family involvement in the person's life. Such homes would be required to provide family-oriented support services.
4. Supports and funding must be flexible enough to allow adjustment to changing individual needs and environments.
5. The family must be supported in staying involved with the family member who is being cared for outside the home.

6. Supports and services must be adequately and dependably funded from public sources and private insurance.

7. Supports and services must be based on the needs and choices of the individual and the family and delivered to the family in the context of the family unit as a whole and its relationship to the community.

8. Supports and services must be accessible throughout the person's life if necessary.

Definition of Medically Fragile:

Medically fragile individuals are those who have medically intensive needs. Their chronic health-related dependence, continually or with unpredictable periodicity, necessitates a 24-hour a day skilled health care provider or specially trained family or foster family member, as well as the ready availability of skilled health care supervision. Further, if the technology, support and services being received by the individual are interrupted or denied, he or she may, without immediate health care intervention, experience irreversible damage or death.

Medically fragile also includes individuals who are at risk for medical vulnerability. These individual's chronic health-related dependence does not require 24-hour supervision by a skilled health care provider, but they do experience unpredictable life threatening incidence. Without appropriate monitoring and the availability of licensed, certified or registered providers, their condition could deteriorate and the intensity of their medical needs increase.

Definition of terms, key components:

Family: natural parents, adoptive parents, extended family and foster parents - a broad, inclusive definition.

Chronic Health-Related Dependence: Ongoing vulnerability to an individual's physical health.

24-Hour/Day Health Care Supervision: 24-hour basis observation by skilled health care providers who are within sight and/or sound of the individual being monitored.

Skilled Health Care Providers: Licensed, certified or registered health care provide (e.g., nurse, physician, respiratory therapist). Also, specifically trained natural or foster family members knowledgeable in the care of the specific individual.

Immediate Health Care Intervention: Skilled health care assistance or treatment necessary to prevent death or damage to individual. Chronology of the need for treatment must be unpredictable.